Communication Matters

Veteran Centered MS Care: Don't Forget the Care Partner!

MSCOE Social Work Education Webinar January 15, 2013



Care and Compassion across the Continuum

Presenters

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Learning Objectives



At the conclusion of this activity, the participant will be able to:

- Describe general and MS specific research about different types of Veteran
 Caregiver relationships.
- 1. Understand aspects of the NMSS "Relationship Matters" toolkit/course
- Understand roles of Social Workers / Providers with MS Caregivers and Veterans.
- 3. Understand why communication skills matter in psychosocial issues with MS Caregivers and Veterans.
- 4. Know the stages and styles of problem solving with MS Caregivers and Veterans.
- 5. Know how to recognize conflict with MS Caregivers and Veterans.
- 6. Know how to recognize safety issues with MS Caregivers and Veterans.



Agenda



Alicia Sloan

- 1. Epidemiology of the Veteran Caregiver relationship
 - Caregiver and MS-specific Caregiver research
- 2. NMSS "Relationship Matters" toolkit/course
 - John Gottman, PhD, research w/relationships
- 3. Roles of Social Workers with MS Caregivers and Veterans

Maggie Kazmierski

- Why does communication matter in psychosocial issues?
- 2. Focusing on problem-solving with the Veteran and Care Partner
 - Stages and styles of problem solving
 - Recognizing conflict
 - Safety issues



Epidemiology of the Veteran and the Caregiver Relationship

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Caregiver Quote

Husband:

"Why are you going [to psychotherapy]? I'm the one with the disease."

Caregiver:

"Well, guess affects all of us!"

It's like I told him, it's like three people in a marriage, and MS is the other person.

(Courts, et al., 2005)



Who are the Caregivers?

Caregivers of Veterans = 462

Spouse/partner	70%
Parent/parent in law	16%
Son/Daughter	9%
Other	5%

(Caregivers of Veterans – Serving the Homefront Study, 2010)





Who are the Caregivers?

	Caregivers of Veterans (n = 462)	Caregivers of non-Veterans (n = 1,307)
Female	96%	65%
Spouse	70%	6%
Lives with care recipient	80%	23%
Primary Caregiver	82%	53%
Caregiving for 10 years or more	30%	15%

Adapted from Caregivers of Veterans – Serving the Homefront Study, 2010.



Impact of MS Caregiving on Young Caregivers

Pakenham (2006)Study, 88 Families

- Young Caregivers: age 10 20, Average age = 14, 46% male
- Parents with MS = Average age = 44 (range 33–55)
- Mothers w/MS = 84%, Mostly Healthy Fathers = 73%
- Higher levels of family responsibilities than children of 'healthy' parents

Identified 4 Domains of Caregiving Tasks

- 1. Instrumental (grocery shopping, housework)
- 2. ADL (toileting, feeding)
- 3. Psycho-emotional (managing the care recipient's emotional difficulties and personality changes)
- 4. Social practical care (providing companionship, assisting with physical exercises)



Costs

- Higher levels of distress and interpersonal difficulties
- Lower life satisfaction and positive affect
- "the parentified child"

Benefits

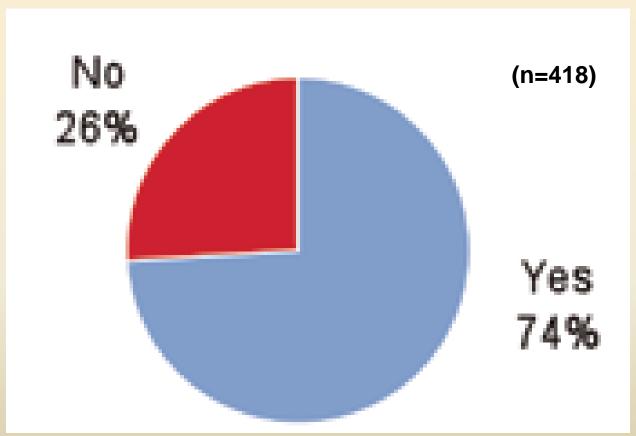
- Self-perceived maturity
- Increased confidence in caring
- Strengthened relationships
- Attachment theory (Bowlby, 1969), youth caregiving may strengthen the parent–child bonds

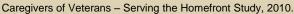


(Arnaud, 1959; Pakenham & Bursnall, 2006; Yahav et al., 2005, 2006, 2007; Ireland & Pakenham, 2010)

Impact of Veteran Caregiving

Marital Strain from Caregivers of Veterans







Impact of MS Caregiving

Impact on Marriage

- Females more likely abandoned/divorced by husband after diagnosis.
- But...motivating factor for CGs
 - marriage vows / commitment to marriage important. (Mutch, 2010)

Impact on Relationships/Family

- 42% Frustrated with care recipient
- 14% Increased arguing with care recipient
- 20% Argues with family members about how to best provide care

(Multiple Sclerosis Caregivers Report 2012)



Perception of Support from Caregiver

MSCOE Research

Male Veterans with MS vs. Female Veterans with MS

 Married males perceive higher level of support from CG than females.



Photo from www.va.gov/MS/Family is Everything.asp

 Males perceived more social support and emotional/information and tangible support than females.

In General

 If greater perceived social and affectionate support from CG, then less depression in Veteran with MS.



(Williams, Turner, Haselkorn, et al., 2004; Bambara, Turner, Williams & Haselkorn, 2010)

Impact of MS Caregiving on Relationships

Benefits and burdens of caregiving:

- Strengthens relationships
- Loss of personal identity
- Limited support systems and resources

More MS Caregiver research needed in these areas:

- How couples cope with relationship changes
- Transition of partner to caregiver
- Develop interventions to facilitate and support role changes and prevent relational strain (Kraft, et al., 2008)





Knight, et al., (1997) Psychosocial Consequences Questionnaire

- 55 Spousal MS Caregivers
- Assessed stress associated with caregiving
- Behaviors causing most distress to Caregivers
 - sudden mood changes
 - partner upsetting other people
 - motor problems
 - incontinence
 - o pain





Mutch (2010) Qualitative Study, 8 Couples

- Examined the experience of Caregiving of spouse with MS
- Major Motivating Factors
 - Commitment of Marriage
 - Marriage Vows



Bing Images



Cheung & Hocking (2004), In-depth Interview MS spousal caregivers

Asked what gives caregivers the courage to "weather illness and adversity in life" and "shape their way of living and coping"?

- ☑ Personal meanings
- ☑ Values
- ☑ Concerns
- ☑ Past experiences
- ☑ Future hopes and dreams
- ☑ Connections with partner and others



Bing Images



Courts, et al., (2005) Husbands and Wives with MS Study

- Four Themes
 - 1. Spouses' role as caregivers: men as protectors and women as advocates.
 - 2. Relationship changes: role changes and strengths.
 - 3. Human and environmental barriers.
 - 4. Need for resources (information about MS, complementary treatments, and support services.)

Relationship Changes: Positive and Negative

- Suffering in silence
- MS had changed their roles. Sometimes led to role reversal.
- Significant disagreements and arguments in marriages previously harmonious and calm before MS diagnosis
- Growth and strength.
- Some stronger marriages and relationships after MS diagnosis. they worked at it.
- Men and women process experiences in different ways



Impacts on Relationships: Caregiver Challenges



Challenges

- 42% Frustration with care recipient
- 14% Increased arguing with care recipient
- 20% Argues with other family members about how to best provide care

Positive Impact

- 74% Positive impact on relationships with care recipient, children and other family members
- 19% Doing new hobbies with care recipient

(Multiple Sclerosis Caregivers Report 2012)

Marriage

- Females more likely abandoned/divorced by husband after diagnosis. (Glantz, 2009)
- But...motivating factor for CGs marriage vows and commitment to marriage important. (Mutch, 2010)



Impacts on Relationships: Communication Challenges

- Caregiver and care partner stress highly correlated
- Caregiver distress / depression
- Interpersonal functioning (hostility and interpersonal sensitivity)
- Making sense of MS diagnosis and impact
- Coping with MS and its effects
- Impact on relationship over time
- Emotional reactivity
- Communication issues between partners, parents, children
- Caregivers struggle to keep their own identity
- Mindfulness and Acceptance Interventions are effective

(Pakenham, 1998, 2008; Pakenham and Samios, 2012; Edmonds et al, 2007; Cheung & Hocking, 2004; Carson, et al., 2004; Wachs and Cordova 2007; Sawyer & Semple, 2010)



National Multiple Sclerosis Society (NMSS)

"Relationship Matters"



- Relationship Toolkit and 8-hour course from National MS Society (NMSS).
- Funded by Department of Health and Human Services, Administration for Children and Families
- Communication skills workbook for couples who want to enhance their relationship.
- Can be used for any relationship/Caregiver and Care Recipient
- Can help make relationships a priority as couples/partners/family members face life with MS together.
 - to communicate better
 - solve problems
 - resolve conflicts
 - stay connected
- www.nationalmssociety.org/everyday-matters/relationship-toolkit/index.aspx
- Download handbook



Building a Healthier Relationship

- Usually involves making changes
- Changes in how you listen and talk to your partner
- Changes in the way you solve problems

General Outline of Workbook

- ✓ Recognize common communication problems and ways to correct them.
- ✓ Understand different couple styles for solving problems.
- ✓ Develop a plan for de-escalating arguments and conflicts.
- ✓ Use effective communication skills for listening and speaking.
- ✓ Learn ways to protect and repair relationships.
- ✓ Discuss MS challenges/concerns
- ✓ Discuss ways to strengthen relationship through renewed commitments to one another.



John Gottman, PhD

- Research on relationship and communication issues w/couples and parents since 1973.
- Gottman's Research: What behaviors most often predict success or failure in a relationship?
 - NMSS "Relationship Matters" Gottman's "What is a healthy relationship?"
- www.gottman.com
 - Smartphone Apps for communication:
 - www.gottman.com/60846/Phone-Apps.html
 - "I Feel" Statements
 - Expressing Needs



Gottman's 6 Tips: "What is a Healthy Relationship?"

1. Edit Yourself

Avoid saying every critical thought when discussing touchy topics.

2. Soften Your "Start-up"

- Arguments "start up" from the get-go by making a critical or contemptuous remark in a confrontational tone.
- Bring up problems gently and without blame.

3. Accept Influence

- A marriage succeeds to the extent that the husband can accept influence from his wife.
- Husband's ability to be influenced by his wife (rather than viceversa) is crucial.
- Women already well practiced at accepting influence from men
- True partnership only occurs when a husband can do so as well.



Gottman's 6 Tips: "What is a Healthy Relationship?"

4. Have High Standards

- Happy couples have high standards for each other even as newlyweds.
- Successful couples refuse to accept hurtful behavior from one another.
- The lower the level of tolerance for bad behavior in the beginning of a relationship, the happier the couple is down the road.

5. Learn to Repair & Exit the Argument

- Successful couples know how to exit an argument.
- Happy couples know how to repair the situation before an argument gets completely out of control.

6. Focus on the Bright Side

- In happy marriages, while discussing problems, couples make at least five times as many positive statements to and about each other, and their relationship, as negative ones.
- A good marriage must have a rich climate of positivity.

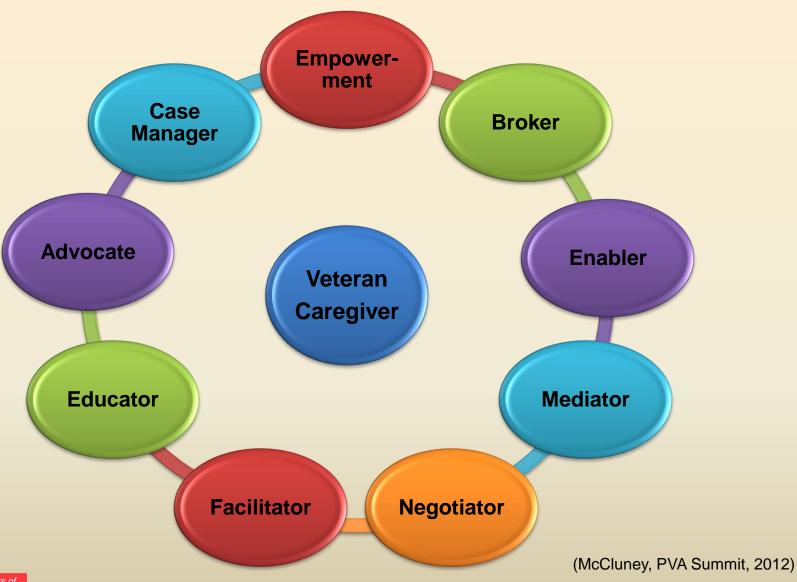


Roles of the Social Worker





Social Work Roles





Roles of Social Workers

Facilitator

- Bring people together:
 Veteran, Caregiver, family, providers.
- Foster an environment of mutual respect and support among all involved.
- Facilitate an open line of communication to you and all involved.

(Baker, 1995)

(Adapted from: McCluney, PVA Summit, 2012)



Roles of Social Workers

Educator

- Provide information and teach skills to Veteran and Caregiver and other provider systems.
- Convey information clearly so it's understood by the Veteran and Caregiver and other entities.

(Zastrow and Krist-Ashman, 1997)

(Adapted from: McCluney, PVA Summit, 2012)



Roles of Social Workers

Enabler

- Help Veteran and Caregiver
 learn the strategies for different situations.
- Convey hope.
- Help reduce feelings of resistance and ambivalence of Caregiving role.
- Help prioritize and break down problems into parts that may be solved more readily.

(Barker, 1995) (Adapted from: McCluney, PVA Summit, 2012)



NASW Standards

- NASW Standards for Social Work Practice with Family Caregivers of Older Adults.
 - Standards and ethics that reflect core elements of social work practice on behalf of family caregivers
 - Advise social workers who address family caregiving needs in various professional settings
 - Can be applied to Caregivers of any population.

www.socialworkers.org/practice/standards/NASWFamilyCaregiverStandards.pdf

(National Association of Social Workers, 2010)



Why Does Communication Matter?

Margaret Kazmierski, MSW, LCSW-C, MSCS MS Centers of Excellence-East VA Maryland Health Care System Baltimore, MD

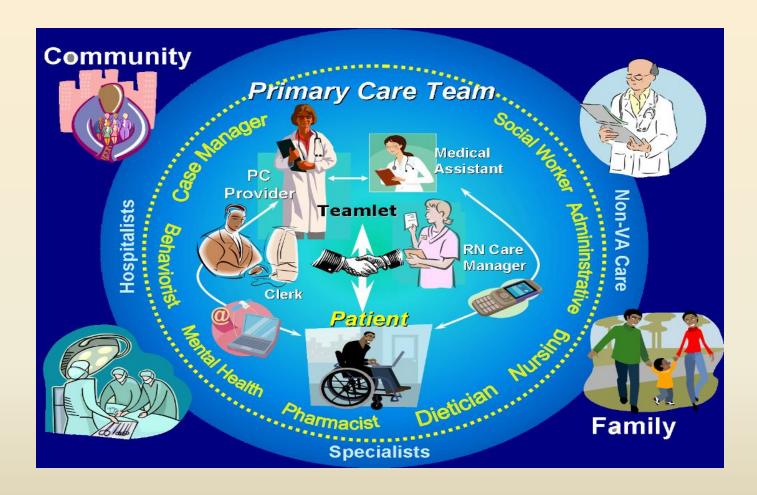


Why Does Communication Matter?

- Patient Centered Care-listening to the needs and concerns of the Veteran and the Caregiver/partner = Better Health Care Outcomes!
- Institute of Medicine (IOM) research connects the dots between communication and better outcomes:
 - Fewer Medical Errors
 - Better patient and carepartner satisfaction
 - Better adherence to TREATMENT PLANS
 - Fewer medical malpractice suits
 - Increased job (provider) satisfaction



PACT MODEL





PHILOSOPHY OF CARE

- Patient Centered Care:
 - Incorporates shared-decision making
 - Encourages self-management
 - Supports self-care techniques
 - Facilitates information sharing and effective communication (use of technology)
 - Ensures coordination across the health care system



PHILOSOPHY OF CARE

- Patient Centered Care:
 - Recognizes psychosocial factors that contribute to effective disease management
 - Continuous use of education, lifestyle coaching, and ongoing communication to deliver whole-person care
 - Effective coordination of resources for optimal function in community



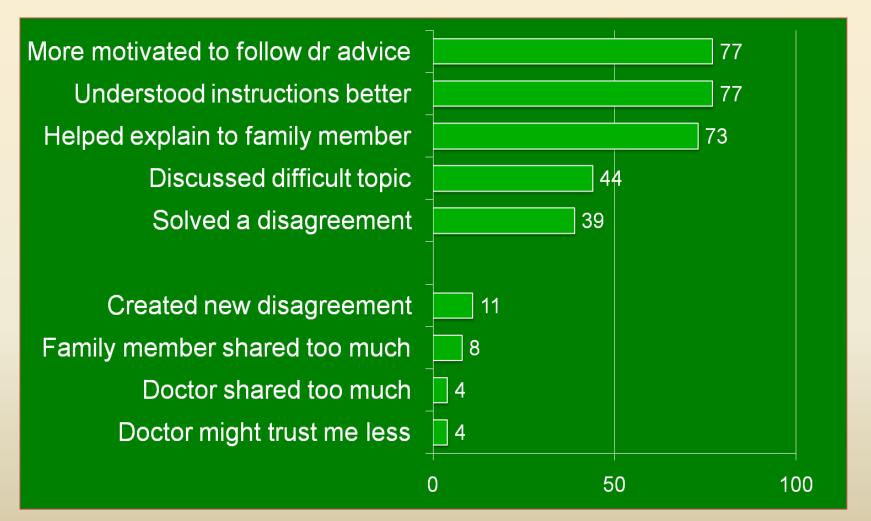
Why Does Communication Matter?

- Improved Communication effects on Patient and Caregiver/partner:
 - Better emotional health for both
 - Better symptom resolution
 - Improved functional status
 - Improved pain control



Why Does Communication Matter?

Consequences of Caregiver Involvement with the Medical Team:





Why Does Communication Matter?

- Health Care is a HUMAN RELATIONSHIP
- Chronic Illnesses, no longer one health management issue
- On-going relationship, not just a focus on cure or curing but MANAGING
- Carepartners influence the outcome of health care management, too.



One Size Doesn't Fit All...















 Stages of problem solving usually follow a familiar pattern for those who address problems intentionally:

Listening:

Using active listening to understand the Veteran's/Caregiver's position on the issue

Persuading:

Once all partners feel understood, they attempt to influence the other's position



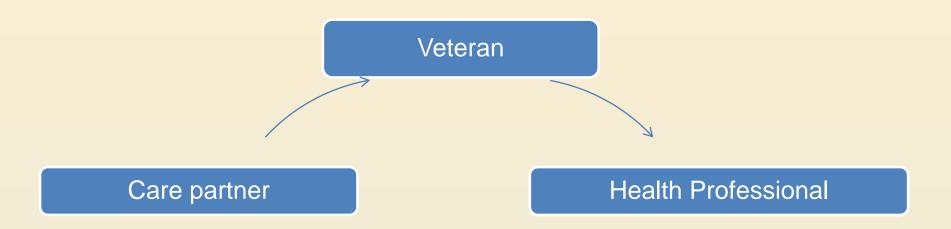
Negotiating:

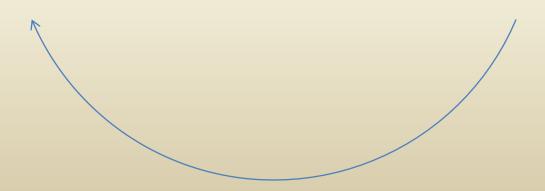
Needs are discussed and everyone reaches a compromise

Compromise:

Everyone agrees to terms that are accepted by all involved in the decision making









Three Different Styles of Problem Solving:

VALIDATING

- Comprise and calmly work out problems
- CONFLICT-AVOIDANT
 - Agree to disagree, rarely confrontational
- VOLATILE
 - Passionate communications, arguments



- Recognizing Conflict (with the couple or within the Provider-Patient-Partner relationship):
 - Conflict is inevitable for most of us
 - Most conflict (59%) between a couple/partnership are unresolved
 - Resolving conflict thru COMPROMISE



- Resolving Conflict:
 - Do not blame
 - Use "I" statements and describe behaviors or situations without judgment
 - Be polite
 - Stick to one request
 - Use Active Listening skills and reflect and clarify



- What's the bottom line for all?
- Define areas of greater flexibility
- Look for a middle/common ground
- Try to understand everyone's point of view (validate)
- Explore common goals
- Explore ways to work towards common goal
- Stay positive



Safety Concerns

- Domestic Violence: Abuse can be physical, sexual, emotional, economic or psychological actions/behaviors that influence another person.
- If a partner is afraid or basic needs are being withheld....contact SW immediately....
- Report suspected abuse.



Resources and References



VA Caregiver Resources

Note: To connect directly to websites listed, make sure you are in "Slide Show" view and hover mouse over hyperlink and click.

- **❖ VA Caregiver Website:** <u>www.caregiver.va.gov</u>
 - VA Caregiver Website Toolbox: www.caregiver.va.gov/toolbox landing.asp
 - VA Caregiver Workbook: www.caregiver.va.gov/pdfs/Caregiver_Workbook_V3_Module_1.pdf
- VA MSCOE website: www.va.gov/ms



NMSS Resources

Note: To connect directly to websites listed, make sure you are in "Slide Show" view and hover mouse over hyperlink and click.

MS and Care Partners Web Page

www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/carepartners/index.aspx

For children, Ages 5-12

Someone You Know Has MS: A Book for Families (.pdf)

Teenagers

When a Parent Has MS: A Teenager's Guide (.pdf)

Families

PLAINTALK: A Booklet About MS for Families (.pdf)

Caregiver self care

Care for the Care Partner (.pdf)



Other Websites for Caregivers

Note: To connect directly to websites listed, make sure you are in "Slide Show" view and hover mouse over hyperlink and click.

Communication Tips & Assisting a Caregiver:

<u>www.familycaregiving101.org/assist</u> <u>www.familycaregiving101.org/assist/communicating.cfm</u>

Consortium of MS Centers (CMSC):

www.mscare.org/cmsc/News/Web-Sights-MS-Caregivers-2.html

- Paralyzed Veterans of America: <u>www.pva.org/site/c.ajIRK9NJLcJ2E/b.6306123/k.B389/Caregivers_Support.htm</u>
- Rosalynn Carter Institute for Caregiving: <u>www.rosalynncarter.org</u>



References from

NMSS "Relationship Matters: A Program for Couples Living with MS"

Note: To connect directly to websites listed, make sure you are in "Slide Show" view and hover mouse over hyperlink and click.

NMSS "Everyday Matters" Program Online:

www.nationalmssociety.org/everyday-matters/relationship-toolkit/index.aspx

Participant Handbook: <u>Download handbook</u>

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QUESTIONS?

COMMENTS?



